

Cultural Effects on Independence and Identity following Brain and Spinal Cord Injury

Carol Bloch, PhD, RN, CTN-A, CNS

Carolyn Bloch, PhD, RN, CTN-A, CNS

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DISCLOSURE

WE HAVE NO CONFLICTS OF INTEREST TO DECLARE.

Sense of Self

- **Everybody has a sense of self or sense of personal identity.**
- **Sense of self is based on the associations of the following combinations : occupations, social relationships, familial relationships, quasi-occupations, avocations, affiliations, abilities/disabilities, salient attributes, and spirituality.**

(Ylvisaker, Hibbard, and Fenney, 2008)

- **Another aspect of self is ethnic identification.**
- **Construction of identity before and after the trauma:**
What was – Who I was
What should have been – Who I wanted to be
What never will be – Who am I now.

Culture

- **Rehabilitation models are not generally adapted to meet the diverse needs of culturally diverse patients in the United States.**
- **Concepts of what caused the trauma, rehabilitation, outcomes to expect from brain and spinal cord injuries have significantly different meanings to diverse patients. The empirical model may not be the answer to the injury but another more profound influence, such as fate, God's will.**

Cultural Beliefs

- **Locus of Control – Who is in charge of your life?**
 - **Good and Bad Behavior are God's Domain.**
 - **Belief in God and a cure is possible.**
 - **One is responsible and in charge of one's own life.**

Cultural Issues to Address

- **Geographic Isolation**
- **Impact of cultural beliefs**
- **Impact of religious beliefs – God determines cause and effect**
- **Reliance of family and community**
- **Lack of knowledge on the rehabilitation process**
- **Language barriers**
- **Misconceptions of brain and spinal cord trauma**
- **Cultural value system and strength of cultural identity**

Cultural Differences

- **Participation in rehabilitation**
- **Outcomes**
- **Distress over role changes**
- **Predictors of acculturation**
 - **intra-group and inter-group differences**

Research Study

One study observed the following in culturally diverse participants post TBI:

- fewer returned to open employment**
- greater reliance on others for assistance with mobility, cognitive activities**
- less social interaction**
- greater distress about change in role in being a homemaker and parent.**

Original Research Study Regarding Employment

Employment linked to TBI survivors lives:

- **Aspects include: community integration, life satisfaction, quality of life, and financial stability**
- **Stable employment is an integral part of successful rehabilitation**
- **Employment rates vary significantly on pre-injury employment, injury severity, disability levels and/or functional independence, education, age and gender.**
- **Race and ethnicity is gaining more attention in research as key factor for employment and return to work.**

Findings

- 1. Minority groups evidenced much greater employment discrepancies relative to rates of the general population.**
- 2. One possible explanation was for this finding is that Whites may have much less social support, which encourages them to return to work before Blacks and Hispanics, who traditionally enjoy stronger social support networks.**
- 3. After catastrophic injury, the families of injured Blacks and Hispanics may be more capable of absorbing the burden of caring for their loved ones at home than the White families.**

(Arango-Lasprilla, et.al., 2011)

Ethnic Minorities and TBI

- **“A greater percentage of TBI misconceptions was associated with having lower education, actively practicing religion, being Spanish, and non-US born.**
- **After controlling for education and actively practicing religion, Spanish-speaking Hispanics reported a greater misconceptions than English-speaking Hispanics and Blacks.”**

Ethnic Minorities and TBI

(Continued)

- **Quality of life/life satisfaction literature review in regards to race and ethnicity observed that there is racial disparities in regards to physical functioning, ADLs, and social/emotional well-being. Focus in clinical practice should be on cultural values and beliefs to the patients and incorporate those aspects into the plan of care.**

(Arango-Lasprilla and Kreutzer, 2010)

Ethnic Minorities and TBI

(Continued)

- **Life satisfaction was studied with the results revealing that based on race/ethnicity African Americans had poorer life satisfaction as compared with Caucasian and Asians 1 year post injury.**
- **Life satisfaction is related to the individual's ability to participate in meaningful activities and to interact with others in a social environment. Family plays an important role in life satisfaction and recovery.**

Ethnic Minorities and TBI

(Continued)

- **Another study revealed that Hispanics had more “somatic” complaints than did Whites or African Americans. Physical and somatic symptoms are acceptable reasons for seeing a doctor because any symptoms of psychological distress are perceived as mental problems and culturally unacceptable.**

(Arango-Lasprilla, et.al., 2012)

Concepts of Culture

- **Rehabilitation will be defined by the culture of the individual not by the provider.**
- **Culturally accepted and expected behaviors on who will make decisions regarding the care and who will give the care, etc. will be made the individual's level of acculturation.**
- **Coping styles vary culturally with resignation, survival, tolerance, and/or excitability, impulsiveness, explosiveness in behavior.**

Personal Story

- **Eileen Rudnick: My Experience with Loss of Self**
“The phrase ‘loss of self’ is used frequently in connection with brain injury. But what does it really mean and how can it affect a survivor? Most importantly, is there a cure? I am a survivor of severe traumatic brain injury, and like many survivors, I have a personal connection to this phenomenon. Feeling disconnected with oneself is the simplest way to describe a very complex reality.”

Personal Story

(Continued)

- **I have reached the final step in Kubler-Ross five stages of grief....Survivors and their families go through it, too, because the loss of someone dear to you can also happen as a result of brain injury. However, the new person can become just as dear to you as the old one. What do we value most, the caterpillar or what emerges from the cocoon?**
- **Brain Injury Association of America**

Take Home Points

- **Cultural beliefs and attitudes toward rehabilitation:**
 - **Cultural groups need a better understanding on traumatic brain and spinal cord injury in relation to recovery.**
- **Providers need to understand the importance of culture in relation to certain roles and outcomes when planning care with culturally diverse patients.**
- **Providers must be the cultural broker within the context of patient advocacy.**